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RUNNING TITLE: Family Social Capital and Reciprocity

Social Capital and the Reciprocal Nature of Family Relationships: the Perspective of Individuals with Mild Intellectual Disability

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Conflict of interest

None

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Keywords

Social capital
Family relationships
Reciprocity
Emotional support

Abstract

Even though family plays a significant role in the lives of individuals with intellectual disability, little research has included their own views about their families. This study examined how 138 people with mild intellectual disability describe their family group, with a focus on the reciprocal nature of the emotional support in relationships with family members. Participants reported "significant" family members beyond the nuclear family, and parents were seen as the main provider of support. Only half of participants had a support relationship with siblings and just 13% of participants reported partners. About 30% of support was reciprocal, and reciprocity varied greatly with the types of family connection (e.g., siblings, peers). Implications for future research as well as practice are discussed.

To enhance social inclusion, there has been recent emphasis on supporting individuals with intellectual disability to forge stronger links with their local community, with the aim of increasing informal social networks of support (Simplican, Leader, Kosciulek, & Leahy, 2015), and reducing support from paid staff. Research on social networks has shown that the informal networks of the majority of individuals with intellectual disability are relatively small and that interactions with people in the wider community are often mainly restricted to family members (Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001; Van Asselt-Goverts, Embregts, & Hendriks, 2013). Family members are also the most significant and main providers of informal support to adults with intellectual disability, along with paid support staff (Sanderson, Burke, Urbano, Arnold, & Hodapp, 2017; Van Asselt-Goverts et al., 2013).

Family clearly plays a significant role in the lives of individuals with intellectual disability. For several decades, research has focused mainly on the impact of having a child with intellectual disability on parental wellbeing or family quality of life, and understanding the factors that reduce or increase psychological difficulties for family members (Hastings, 2016). Researchers have also considered research questions in the reverse direction – how family members' behaviors, well-being and family relationships may affect individuals with intellectual disability. In particular, individuals with intellectual disability are at increased risk for the development of psychological problems, and factors associated with this increased risk include family dysfunction and parental psychological distress (Dickson, Emerson, & Hatton, 2005; Wallander, Dekker, & Koot, 2006). Several researchers have also addressed the bidirectional nature of the relation between parental and family dysfunction and psychological outcomes for the family member with a disability (Greenberg, Mailick Seltzer, Hong, & Orsmond, 2006; Orsmond, Mailick Seltzer, Wyngaarden Kraus, & Hong; 2003). For example, in a longitudinal

study, Orsmond et al. (2003) followed 193 families of adults with intellectual disability over a six-year period. They found that initial levels and changes over time of adult behavior problems predicted changes in maternal well-being, while initial levels and changes of maternal well-being also predicted later behavior problems of adults with intellectual disability.

Despite the recognition that family is an important context for the development and well-being of children and adults with intellectual disability, very little research has considered directly the perspective of people with intellectual disability about their families. Therefore, the primary aim of the current study was to examine the way in which people with mild intellectual disability perceive the support within their family. As people with intellectual disability are the experts on their own lives, experiences, and feelings (McDonald, Kidney, & Patka, 2013), it is important to build a research programme about how people with intellectual disability conceive of their family as well as the impact their family has on their lives. Existing research has included a small number of qualitative studies about the family-related experiences and perspectives of people with intellectual disabilities (e.g., Kramer, Hall, & Heller, 2013; Walmsley, 1996; Williams & Robinson, 2001). For example, Kramer et al. (2013) found that reciprocity in sibling relationships seemed to consist of siblings with disabilities enacting their family roles (e.g., unclehood or aunthood) in exchange for their nondisabled siblings providing them access to resources in the community. Their study showed that social capital is a useful theoretical framework in understanding support in family relationships.

Social capital is defined as the resources that flow to individuals from their possession of a durable social network of mutual recognition (Bourdieu, 1986). As families may function as a primary source of social support for all individuals, they are a significant source of social capital (Furstenberg & Kaplan, 2004). From this perspective, positive and supportive family

relationships (i.e. family-based social capital) are likely to promote an individual's physical and mental health (Kawachi & Berkman, 2001; McPherson et al., 2014; Riumallo-Herl, Kawachi, & Avendano, 2014). Social capital is about the mutual exchange of supports or resources between individuals (Bullen & Onyx, 1999). Exchange within close relationships such as family is not based on an "immediate return" requirement, but more on the assumption that someone will return the favor at some later point and equivalence or reciprocity will be achieved eventually (Antonucci & Jackson, 1990; Torche & Valenzuela, 2011). However, Gouldner (1960) argued that the norm of reciprocity might not apply to certain groups of people, such as children, the elderly, or people with disabilities. In these cases, reciprocity might fail and the norm of beneficence emerges in which people who are able to assist and support others do so regardless of the recipient's future ability to reciprocate (Gouldner, 1973). Being able to provide support may enhance feelings of self-worth and self-esteem (Forrester-Jones & Barnes, 2008; Liang, Krause, & Bennett, 2001). As such, it has been shown that an over-benefited position with more received than given support may lead to a less positive outcome for the individual in terms of mental health and wellbeing than more balanced relationships or an under-benefited position (Fyrand, 2010; Thomas, 2010).

Individuals with intellectual disability have also recognized reciprocity as a key feature of significant relationships and emphasized the importance of reciprocity in relation to their self-worth (Milner & Kelly, 2009). Reciprocity is important to them to challenge feelings of dependence and to make them feel useful, though they also felt that they do not often have the chance to reciprocate (Milner & Kelly, 2009). For example, individuals with mild intellectual disability (IQ in the range 50-70, American Psychiatric Association, 2000) may highly value relationships with support staff (Van Asselt-Goverts, et al., 2013; Giesbers, Hendriks, Jahoda,

Hastings, & Embregts, 2019). However, as these relationships are often of a unidirectional nature, people with mild intellectual disability may also express discomfort with these relationships and a wish for reciprocity (Forrester-Jones et al., 2006; Giesbers et al., 2019). These findings stress the importance of access to family-based social capital (i.e., being able to receive and contribute support and to experience reciprocity within the family) for people with mild intellectual disability.

In addition to Kramer's et al. (2013) qualitative study, there has been some published quantitative research focused on the families and supports of individuals with mild intellectual disabilities from a social capital theoretical perspective, using family network methodology developed for the general population. For example, Widmer, Kempf-Constantin, Robert-Tissot, and Carminati (2008) examined the ways in which 24 individuals with mild intellectual disability, 24 individuals with mild intellectual disability and comorbid psychiatric problems, and a non-clinical sample of 24 students perceive their family group. Family-based social capital was found to be strongly influenced by the presence of intellectual disability. Individuals with mild intellectual disability had less supportive, and fewer supported, family members than individuals without intellectual disability. Also, the family members belonging to their networks were less interconnected in terms of supportive relationships (i.e., lower network density), and their networks contained more disconnected family subgroups. Disconnected subgroups do not have any support relationship with other members in the network (outside the subgroup). These findings were even stronger for individuals with mild intellectual disability and comorbid psychiatric problems (Widmer et al., 2008). In a second study, the composition of the family group of 40 individuals with mild intellectual disability was also found to be distinct from the general population, as spouses/partners and children were often missing (Widmer, Kempf, Sapin,

& Galli-Carminati, 2013). However, these findings did not imply that individuals with mild intellectual disability were necessarily isolated from family members, as they had a broader conception of family and social capital, by viewing friends, step-family, and professionals as members of their "family" group. Finally, perceptions about family were also found to be dependent on living situation; for individuals living at home, the nuclear family was most prominent, whereas the perceived family groups of individuals living in community residences included more friends and professionals (Widmer et al., 2013).

Even though existing research and theory emphasizes the need for reciprocal relationships for individuals with intellectual disability, still little is known about how these individuals perceive the reciprocal nature of the relationships within their family groups. As individuals with intellectual disability are the experts and authorities on their lives, experiences, and feelings (McDonald, Kidney, & Patka, 2013), it is also important to gain a broader understanding of the experiences of family support, and to systematically describe how they define their family groups and supportive relationships. A limited number of quantitative studies (e.g., Widmer et al., 2008, 2013) has examined supportive relationships and social capital in families from the perspective of individuals with mild intellectual disability. However, this previous quantitative work did not address the reciprocal nature of relationships within families, which is, as stated, one of the key features of social capital. In addition, it has not used family network methodology that has been adapted specifically for people with intellectual disability (Giesbers, Tournier, et al., 2019), and has relied on small purposive sampling for exploratory studies. Therefore, the current study builds on previous research by examining quantitatively the way in which individuals with mild intellectual disability define their family group as well as the social capital their families provide in a relatively large sample (N = 138) of individuals with

mild intellectual disability. More specifically, the research questions for the present study were: (1) how do individuals with mild intellectual disability define their family, (2) who do they consider to be their "significant" family, (3) what emotional support relationships with family members do they describe, and (4) how do they perceive the reciprocal nature of the emotional support relationships within their family? The current study focused on people with mild intellectual disability, because the family network methodology that has been adapted for use with people with intellectual disability was found to be feasible for people with mild intellectual disability, but not for those with more severe levels of intellectual disability (Giesbers, Tournier, et al., 2019). As family support has been found to be dependent on living situation (Widmer et al., 2013), we focused on one living situation only (individuals with mild intellectual disability living away from their birth family with support from a service provider).

Method

Participants

INSERT TABLE 1 ABOUT HERE

Inclusion criteria for participants were: 1) a mild intellectual disability (IQ 50-70) according to file records, 2) aged between 18 and 40 years, and 3) receiving support from paid staff at least once a week for a minimum of six months. The limit for inclusion was set at 40 years old, since parents of older individuals are likely to be elderly and less able to provide

support (Bigby, 2008). As family support is found to be dependent on living situation (Widmer et al., 2013), living with their birth family was an exclusion criterion for participants. A total of 138 individuals with mild intellectual disability (IQ 50-70) participated in the study, and 56.5% (78) were male. Participants' age ranged from 18 to 40 years (M = 28.2, SD = 6.14). Additional demographic characteristics are described in Table 1.

Recruitment

After ethical approval was obtained from the Ethical Review Board of Tilburg University (EC-2015.46), participants were randomly selected from five service providers for people with intellectual disability in the Southern part of the Netherlands. A stratified sampling procedure (i.e., stratified by service provider) was used to increase the representativeness of the sample. First, each service provider was asked to identify the total number of their service users who met inclusion criteria. Second, it was ensured that, from each provider, service users who met inclusion criteria were proportionally included in the study (10% from each service provider to reach the target number of about 150 participants). As a result, the number of participants per service provider varied from 14 to 50. See Figure 1 for an overview of the sampling procedure.

INSERT FIGURE 1 ABOUT HERE

Recruitment of participants always took place in consultation with the key support worker. After the aim and procedure were explained by the researcher on the telephone, an information letter was sent to key support workers and they were asked to discuss the letter with the selected service users. This letter included information about the aim and content of the study, the financial reward for participation (ten euro cash), and the confidentiality of the data.

Key workers of 354 individuals who met inclusion criteria were asked to invite them to participate in the study, of which 150 participated (42.4%). In the majority of cases of non-response, the invited person decided not to participate (*n* = 117, 57.4%). Other reasons for non-response were that, before the person with mild intellectual disability was invited, support staff and/or psychologists advised against participation in the study (e.g., the expected burden was too high; *n* = 59, 28.9%), or relatives/guardians did not agree with inviting the person to participate (*n* = 21, 10.3%). In these situations, the researchers decided to respect their wishes and the person with mild intellectual disability was not invited. Another reason for non-response was that some staff were unable to facilitate participation of individuals with mild intellectual disability due to high workload and time constraints, and were not able to cooperate with the researchers (*n* = 7, 3.4%). For those individuals with mild intellectual disability who were invited and accepted the invitation to participate, an appointment was made at their home or another location they preferred.

Measures

Family networks. The Family Network Method – Intellectual Disability (FNM-ID; Giesbers, Tournier, et al., 2019) was used to question individuals with mild intellectual disability about their family networks. The original Family Network Method (Widmer, Aeby, & Sapin, 2013) was adapted for use with people with mild intellectual disability (Giesbers, Tournier, et al., 2019). The FNM-ID is a detailed approach, which maps the family network and identifies the significant family members of the participant, as well as the family members who provide emotional support.

The FNM-ID consists of four steps. In the first step, participants are invited to map their family network. The term ‘family’ is deliberately left undefined by the interviewer; participants

are instructed to use their own definition and say who they consider to be their family. The names of all cited family members are written down on separate cards, including a card with the name of the participant. In a second step, participants are instructed to define their significant (according to their own definition) family members from those cited at step one: "Which members of your family are significant to you?" A green and a red box are used to support the participant to make their decision; cards for family members who were considered significant are put in the green box, the cards of the family members who are considered not significant are put in the red box. Alternative formats for this question are used as prompts (in a fixed order) when a participant is not able to answer this main question about significance of family. The third step concerns questions about the provision of emotional support. Participants not only estimate their own relationships with their family members (in terms of emotional support), but also the relationships existing among all family members. That is, after participants are asked who they feel supported by when feeling "out of sorts", the same question is asked for all other members of the family network. For example, participants are asked: "when your brother is feeling out of sorts, who is there for him?". "Feeling out of sorts" is a British translation of the original phrase that we have used in the Dutch language. The original phrase is common, everyday language in Dutch. In addition, alternative formats for the question are available as prompts to facilitate understanding, and the green and red boxes are used to support the participant. In the fourth step, participants are asked to estimate their own significance for other family members: "To which of your family members are you significant?" and the same procedure for alternative prompts, and the green and red boxes, is used. Additionally, key demographic characteristics of all cited family members (e.g., gender, age, place of residence) are gathered.

Cognitive ability. To check whether a participant met the inclusion criterion for the study of having a mild intellectual disability, an estimation of the IQ-scores was made, based on subtest standard scores. The subtests 'Vocabulary' and 'Matrix Reasoning' from the fourth edition of the Dutch Wechsler Adult Intelligence Scale (WAIS-IV; Wechsler, 2012) were used in this study, as these two subtests correspond with the two-subtest form of the Wechsler Abbreviated Scale of Intelligence (WASI-II; Wechsler, 2011). The WASI-II is an abbreviated version of the WAIS-IV and was developed as a screening tool. However, no Dutch version of the WASI-II was available and therefore the two corresponding WAIS-IV subtests were administered to participants.

Procedure

Data were collected by the first and fifth author, and a research assistant. Participants were visited individually by one of the researchers for approximately 45 to 60 minutes per visit. In some cases (6.7%), the participant was not able to complete all measures during one visit (as they showed signs of distractibility, fatigue, and restlessness, or they themselves indicated that they would like to complete the measures at another time). In those cases, a second visit took place. Each visit started with a brief conversation to put the participant at ease after which participants were asked to give their informed consent. To ensure that participants could give their informed consent, a standard consent procedure was followed (Arscott, Dagnan, & Stenfert Kroese, 1998). After giving participants a verbal and written overview of the research project, the researcher determined whether participants could recall: (i) the general content of the proposed questions; (ii) that they would be interviewed once or twice, (iii) possible favorable and adverse aspects of participation in the study, and (iv) that they would be free to withdraw at any time. If necessary, the researcher explained these four points in more understandable or

alternative words until the participant was able to understand the key aspects of the research project. After consent was given, WAIS-IV subtests were administered, according to the prescribed procedure (Wechsler, 2012). Second, demographic characteristics were collected by a computer-administered set of questions. Since it was expected that not all participants were able to read the items, and to maintain the same procedure for all participants, the researcher and participant both sat behind the laptop and the researcher read each item out loud. The participant verbally indicated the response and either the participant or the researcher recorded the response. Participants were then interviewed about their family network using the FNM-ID, following the prescribed interview protocol (Giesbers, Tournier et al., 2019). The FNM-ID interview protocol has been developed by the current authors. As such, the first and fifth author trained and supervised the research assistant in implementing the FNM-ID protocol and additional supervision and discussion of procedural issues took place throughout the study within the whole research team. In addition, with permission of participants, all FNM-ID interviews were audio recorded. To check for the fidelity of the implementation of the FNM-ID procedure, the three researchers checked 10% of each other's audio recordings of the interviews; no significant deviations from the interview protocol were found. FNM-ID were also audio recorded to ensure that all data were captured. The aim was to establish a conversational tone with the participants, and it was difficult for the researcher to maintain the natural flow of the questions while writing down all the participants' answers. After completion of all measures, participants received their financial reward. After the visit, with the consent of participants, the researcher contacted the psychologist or key support worker for each participant in order to check for additional diagnoses (official diagnoses according to file records). Also, the scores on the WAIS-IV subtests were converted into standard scores. For 11 participants, both standard scores were

indicative of a level of cognitive ability above or below the mild intellectual disability range (taking the standard error into account). Therefore, the data of these 11 participants were excluded from the analysis. This additional check on mild intellectual disability was included in the study because file scores were often missing, outdated, or obtained using unidentified IQ tests.

Data Analysis

Family network data were entered into Excel. Excel files were imported in and analyzed using UCINET (Version 6.623; Borgatti, Everett, & Freeman, 2002), a software package for the analysis of social network data. The social network analysis concerned three overlapping sets of family networks: (1) the full family network (i.e., all the listed family members), (2) the significant family network, and (3) the family members perceived by participants as providing them with support (in-neighborhood; Hanneman & Riddle, 2005), or depending on them for support (out-neighborhood; Hanneman & Riddle, 2005)(Giesbers, Tournier, et al., 2019). For each set of family members, the size (i.e., number of network members) and the composition (i.e., composition in terms of the nature of the relationship to the participant, such as the number of parents, siblings, and friends that made up the network) were calculated. Also, the direction of support for each of the participant's relationships (received, given, or reciprocal support) was measured. Subsequently, for each type of relationship (e.g., parent, sibling) the proportions of received, given or reciprocated relationships were calculated. Data from the social network analysis for one participant were excluded from further analysis; scores on all but one measures were found to be extreme outliers (three or more standard deviations above the mean).

Results

Definition of the Family

Participants listed a mean of 9.98 (*SD* = 6.28, range: 1 – 34) family members. The most frequent numbers were that family networks consisted of six or seven members (both in 10.1% of cases).

Listed family members were categorized into 12 types based on the nature of the relationship to the participant (e.g., parent, extended family, or friend). See Table 2 for an overview of the composition of family networks of individuals with mild intellectual disability in terms of the nature of the family relationship.

Significant Family Members

On average, participants considered 6.18 family members of the 9.98 full family members to be "significant" (*SD* = 4.86, range: 1 – 26). Seven participants perceived only one family member as being significant (5.1%). Most frequently, participants listed four significant family members (17.4%), and 50.7% of participants listed no more than four significant family members. Participants felt that they were themselves significant to 5.52 (*SD* = 4.87, range: 0 – 26) of their 6.18 significant family members (i.e., mutual significance). Three participants did not feel they were significant to anyone in the network (2.2%), and the modal number was that participants felt mutually significant to four network members (21.2%).

Table 2 also describes the nature of the relationship with the significant family members. Compared to the full family network, the number of times the family member type was listed by

participants declined for nearly all categories, except for partners and children, meaning that listed partners and children were always in the significant network. Six out of the 131 participants who listed parents in their full family network, did not include any parent in their significant network. The small decline in mean number of listed parents (from 1.64 to 1.55) shows that most participants considered all parents as significant. With regard to siblings, both the number of participants that listed siblings as well as the mean number of listed siblings are lower compared to full family networks. This was also the case for extended family, step-family, and family in-laws.

All participants who included foster family, professionals, and volunteers in their full family network, also included foster family members in their significant network, though the mean number of members that were listed was lower. When it comes to friends and other relationships such as colleagues or neighbors, both the number of participants that cited the term and the mean number of significant friends and other members decreased. Even though based on small numbers, these findings indicate that professionals, volunteers, friends and other members who were regarded as part of their family, were not always considered to be "significant" family members.

INSERT TABLE 2 ABOUT HERE

Receiving and Giving Emotional Support

This subsection involves the subset of family members who are perceived by participants as providing them with emotional support (in-neighborhood; Hanneman & Riddle, 2005), or depending on them for support (out-neighborhood; Hanneman & Riddle, 2005). Participants reported feeling supported by a mean of 2.34 family members (*SD* = 1.60, range: 0 – 7). Of the

participants, 7.2% (10) indicated that they did not feel (emotionally) supported by anyone in their family. The most frequent numbers were that participants felt supported by two family members (30.4%) or had one supportive person in their family network (26.8%). Participants reported being a supportive person for a mean of 2.37 family members (*SD* = 3.54, range: 0 – 26). Thirty-six percent of participants (49) did not consider themselves as a supportive person for anyone in the family, which was the most prevalent answer among participants. When a participant did see themselves as supportive to other family members, this was most frequently related to one other person (20.3%). Of the ten individuals who did not believe they received support from anyone in the network, six did not think that they provided support to anyone in their family, meaning that those six had no supportive connections with any family members.

Table 3 (left columns) presents the nature of the emotional support relationships (i.e., number of participants that listed the relationship(s) and total number of relationships). Parents were reported to be the main support provider and participants had the most supportive relationships (all directions) with parents. This was followed by extended family and siblings. However, only about one-third of participants reported these supportive relationships with extended family, meaning that this sub-group of participants had, on average, relationships with quite a few (2.84) extended family members.

Reciprocity of Emotional Support

Even though the mean numbers of relationships with family members in which support is given or received were found to be nearly equal, this finding does not necessarily imply that participants' relationships were viewed as reciprocal. Table 3 (right columns) provides an overview of the direction of relationships per type of relationship, indicating whether the relationship includes only received support, only given support, or reciprocal support. Overall,

30.6% of participants' support relationships were reciprocal, and 34.4% of participant's relationships only consisted of received support with 35.0% of relationships only included given support.

INSERT TABLE 3 ABOUT HERE

Table 3 also shows that the percentages per direction of relationships varied by the type of the relationship. First, relationships with peers (i.e., partner relationships and friendships) had a relatively high (above average) reciprocity. In some cases (29.4%, $n = 5$), participants reported that they were only providing support to partners and friends, though they never experienced receiving support from them without giving support. In contrast, relationships with extended family members show the lowest level of reciprocity and participants believed to predominantly provide support to their extended family such as nieces/nephews, aunts/uncles, cousins, and grandparents. Lastly, relationships with siblings in which support was given or received, were the most balanced.

Using the FNM-ID, participants not only estimated the relationships between themselves and their family members, but also the relationships among all their family members (e.g., mother – sister). This estimated reciprocity of relationships among all family members in the participants' family networks was found to be 35.1% on average (not in table), as opposed to one-sided relationships in which it is estimated that only one family member provides support (64.9%). Thus, participants perceived only slightly greater levels of reciprocity in the relationships among the remainder of their family network than they perceived between themselves and their family members.

Discussion

This study is the first to systemically examine how a relatively large group of individuals with mild intellectual disability, who lived apart from their natural family, describe their family network and how they perceive the emotional support relationships with their family members and the reciprocal nature of these relationships. In the current study, it was not predefined for participants what constitutes their family. As such, participants may have used not only broader, but also narrower definitions than more traditional definitions of the concept family.

The findings of the study show that individuals with mild intellectual disability describe a variety of family groups, including significant family members beyond the nuclear family, such as extended family, in-laws, step-family, and friends. According to participants, the nuclear family of origin, and especially parents, played a prominent role in their social capital. That is, in total, participants had the highest number of relationships with parents and their parents were seen as the main support provider, which is in line with the reports of family members' themselves in terms of more practical support (Sanderson et al., 2017). In addition, even though only about one-third of relationships with parents were considered reciprocal, individuals with mild intellectual disability may also see themselves as being supportive to their parents. In a few cases (10% of reported relationships with parents), participants thought that they were supportive of their parents even though they did not feel this was reciprocated.

Siblings were considered to be part of the nuclear family of a large group (about 90%) of participants. However, smaller groups of participants considered their siblings as significant to them (70%), or experienced a support connection with them; only half of participants reported a support relationship with (a) sibling(s). The number of relationships with siblings in which support was given and received was found to be quite balanced, as participants reported a nearly

equal amount of relationships with their siblings in which support is given, received or reciprocated. In addition, it occurred that participants fulfilled a supportive role to their nieces and nephews. Interestingly, Kramer et al. (2013) found that reciprocal relationships among siblings with and without intellectual disability consisted of people with intellectual disability enacting specific family roles, such as fulfilling a role as an aunt or uncle, in exchange for their siblings providing them with access to resources in the community. However, the current study also shows that half of participants did not report support relationships with siblings. This finding is important in terms of the sustainability of their family-based social capital, as the life expectancy of individuals with intellectual disability has increased (Dieckmann, Giovis, & Offergeld, 2015), and the life expectancy of individuals with a mild disability may equal the expectancy for the general population (Bittles et al., 2002). This means that parents may no longer fulfill a key support role for the duration of their child's whole life. Older parents are likely to have increasing health problems and lower energy levels to provide support to their child with intellectual disability (Grey, Griffith, Totsika, & Hastings, 2015), and parents will die before their offspring.

The finding that partners and/or children were seldom (13%) part of participants' family networks is also of importance (Widmer et al., 2008; Widmer et al., 2013). Individuals with mild intellectual disability may often be missing this potentially significant source of social capital (Soulsby & Bennett, 2015). Partners were significant to participants, and research has shown that many individuals with an intellectual disability have expressed a desire for an intimate relationship, as these relationships may meet their needs for support, companionship, love and affection (Giesbers, et al., 2019; Healy, McGuire, Evans, & Carley, 2009; Rushbrooke, Murray, & Townsend, 2014).

Social capital is about the reciprocal exchange of supports (Bullen & Onyx, 1999). By not only receiving, but also contributing support, it is possible to build continuing relationships and exchanges. On average, participants had an equal amount (both about 2.3) of relationships with family members in which support was given and/or received. This finding indicates that, as a group, individuals with mild intellectual disability may not have a sense that they receive more support from others than they give (Gouldner, 1973). However, only 30% of participants' relationships were reciprocal and they estimated the support relationships between themselves and their family members as slightly less reciprocal than they estimated the overall reciprocity in their family networks. Moreover, substantial differences within the group of participants existed. About one third of participants did not believe that they fulfilled a support role for anyone in their family network. Earlier research pointed to the fact that such an over-benefited position may have a negative influence on self-worth and self-esteem (Forrester-Jones & Barnes, 2008; Liang, et al., 2001).

The ratio of given, received or reciprocated support also varied by the type of family relationship. Even though based on small numbers, relationships with partners and friends are relatively often (about 70% and 65% respectively) based on mutual support, a finding that highlights the potential and significance of intimate relationships and other peer relationships for individuals with mild intellectual disability (Friedman & Rizzolo, 2018; Neuman & Reiter, 2017). In contrast, participants had relatively few (13%) reciprocal relationships with extended family members (i.e., aunts/uncles, cousins, grandparents, and nieces/nephews), which seemed to be related to the relatively high number (70%) of unidirectional relationships with given support. Therefore, extended family seemed to be an important group within the family network, where

participants felt they contributed in terms of providing support, though only about one-third of participants included extended family in their (significant) family network.

Limitations and Implications for Future Research

The results of the present study need to be considered within the context of a number of limitations. First, only 42.4% of the selected individuals who met inclusion criteria participated in the study. Therefore, a risk of non-response bias exists that may have negatively affected the representativeness of the sample. No other data were available for the non-respondents. Therefore, it was not possible to quantify biases in the sample selection. Second, the findings concerned a specific group of individuals with mild intellectual disability; all lived apart from family and were frequently supported by staff from a service provider. Future research should address the perspective of individuals with mild intellectual disability in different kinds of support arrangements. Third, even though the current study gives a detailed and valuable insight into the family support experiences of individuals with mild intellectual disability, it did not include a comparison group of individuals without intellectual disability. As such, this study does not provide insight into how the characteristics of the (significant) family networks and the support experiences of people with a mild intellectual disability compare to the network characteristics and family support experiences of people in the general population. Future research should include a comparison group to assess explicitly how the presence of a mild intellectual disability may influence access to family resources such as (reciprocal) emotional support. Also, while earlier research pointed to the fact that an over-benefited position with more received than given support may have a negative influence on the self-worth and self-esteem of the individual (Forrester-Jones & Barnes, 2008; Liang, et al., 2001), the current study was descriptive in nature and did not include such measures. It might be of interest for future studies

to examine whether there are associations between reciprocity and the balance between given and received support of the individual on the one hand and experiences of self-worth and self-esteem on the other. In addition, the current study included a one-time data collection. Therefore, it would be important in future research to administer the FNM-ID in a longitudinal design to explore the robustness of reported family network data over time. Last, this study included quantitative family network data of a relatively large group of participants. It might be of interest for future research to include an in-depth exploration of how a smaller group of people with mild intellectual disability defines family members as significant and how they feel emotionally supported by, and emotionally supportive for, the family members of their choosing.

Implications for Practice

The current study showed that adults with mild intellectual disability were mainly dependent on their parents for their family-based social capital, while siblings might be more at distance. However, the involvement of siblings in the lives of people with intellectual disability may be of great importance. Even though siblings are often expected to fulfill a key role in future support (Greenberg, Mailick Seltzer, Orsmond, & Wyngaarden Krauss, 1999; Heller & Arnold, 2010), parents may be reluctant to plan for the future and to involve siblings in their planning (Heller & Kramer, 2009). Therefore, it is important to involve siblings in support and future planning early on, as current sibling relationships may influence their future support expectations. In previous research, siblings had higher support expectations if they currently had more contact with their siblings with a disability and provided them with more support (Heller & Kramer, 2009). Therefore, staff and service providers should be aware of the important role that siblings play in the lives of their brother or sister with a disability, and their need to be involved in current and future support. In order to foster positive relationships, staff should also focus on

the support that people with intellectual disability may be able to offer their siblings. As already stated, reciprocity helps to ensure continuing relationships and exchanges. Therefore, to build social capital in sibling relationships, it is important for staff to encourage reciprocity (Kramer et al., 2013; Smith, Greenberg, & Mailick Seltzer, 2007).

Moreover, while showing potential in reciprocal support provision, partners were seldom included in the family networks. Intimate relationships may contribute to the quality of life and sense of self-worth of people with mild intellectual disability (Neuman & Reiter, 2017; Rushbrooke et al., 2014). In addition, the absence of an intimate relationship has been shown to leave some individuals feeling unfulfilled and unable to achieve the ordinary future they want, settling down, getting married and having a family (Neuman & Reiter, 2017; Rushbrooke et al., 2014). As such, extra staff training with regard to this topic might be needed (Bates, Terry, & Popple, 2017). It is important for support staff and family members to recognize the value of intimate relationships for people with intellectual disability, and to support them in forging and maintaining these relationships instead of being overprotective and controlling which could have a negative impact (Bates et al., 2017; Healy et al., 2009).

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